Eligibility Subcommittee Meeting #1 January 31, 2007
10:00 AM to 1:00 PM

ITEM	DISCUSSION	ACTION
Purpose of the Subcommittee	This group is charged with determining the beneficiaries within CCS that will be eligible to receive the waiver pediatric palliative care benefit.	
Marian Dalsey, M.P.H., M.D., Chief, Children's Medical Services Branch (CMS) Introductions	Committee Members who were present (in person or on phone) introduced themselves and their programs: Devon Dabbs: Children's Hospice & Palliative Care Coalition Lori Butterworth: Children's Hospice & Palliative Care Coalition Christy Torkildson: George Mark Children's House John Golenski: George Mark Children's House Jenny Mann Francis: U.C. Davis Medical Center Wendy Longwell: Parent Shannon Snow: Parent Louis Girling, M.D.: Medical Director, Santa Clara County CCS Wayne Spruce, M.D., Medical Director, San Diego County CCS Mary Jess Wilson, M.D., Medical Director, Sacramento County CCS Marian Dalsey, M.P.H., M.D., Chief, CMS Branch Chester Randle, M.D.: Chief, CMS Branch Program Development Section Pam Christiansen: Nurse Consultant, CMS Branch Jan Burrow: Nurse Consultant, CMS Branch Sharon Lambton: Nurse Consultant, San Francisco Regional Office Belva Kinstler: Health Program Manager, CMS Branch Xavier Castoreno: Social Work Consultant, CMS Branch Carmen Romo: Research Analyst, DHS, MCP-RDB Kathy Bissell-Benabides: Health Program Specialist, DHS, MCP-RDB Erin Winter: Staff Services Analyst, CMS Branch	

ITEM	DISCUSSION	ACTION
Marian Dalsey, M.D.	Handouts for group members: • CCS medically eligible conditions from CCS website • Dr. Dalsey's table showing frequency of specific CCS conditions that may be considered life-limiting • Other states eligibility criteria: Washington, Utah, Colorado, and Florida • New England Journal of Medicine, April 22, 2004 Table 1. Conditions Appropriate for Pediatric Palliative Care • Feudtner National Trends, published by the American Academy of Pediatrics • Feudtner Patterns, published by the American Academy of Pediatrics • Hays Satisfaction article: *The Seattle Pediatric Palliative Care Project: Effects on Family Satisfaction and Health-Related Quality of Life*	
Defining Eligibility Population	Minimal requirements in AB 1745: • Up to 21 years of age • Have a CCS medically eligible condition • Have a serious condition that requires palliative care **Dr. Dalsey** reviewed the table showing frequency of specific life-limiting CCS conditions. Only the primary diagnosis in CMSNet is listed. This survey is limited, as the ICD-9 diagnostic coding system does not specifically target the pediatric population. Other factors impact pediatrics and must be considered. CP is not included here, although some cases may fit. This table does not reflect severity of illness or children with multiple diagnoses. This is just to give you an idea. See the *Hays Satisfaction* article pie chart, showing percentage distribution of diagnostic categories of enrolled children. **Dr. Spruce:** We must be selective. Many AML and Wilms tumor cases are cured. **Lori:** A benchmark for severity criteria may be needed. **Dr. Spruce:** What services are already offered and currently available for authorization? CCS SCCs have broad spectrum-medical, nursing, MSW, and	

	Chaplaincy services, with a multidisciplinary team approach. **Dr. Randle:** Yes, but they may not have the intense care coordination needed to address palliative care. The palliative care model is ideal from time of diagnosis. **Jenny:** UCD has Psychology and Social Services staff working across SCC teams with the SCC MSW. No spiritual services are offered, but even this approach is not as comprehensive as needed. **Lori:** This underscores the necessity of waiver to deal with hospice Medicare eligibility laws. What is already available? What is necessary for the waiver program? **Wendy:** Why won't waiver services be available statewide? **Dr. Dalsey:** Additional services designated for the waiver will not be available statewide--only in pilot sites identified in the waiver. **Dr. Spruce:** A smooth transition of care is necessary, which will require a dedicated and coordinated approach, in addition to the child's SCC and/or specialty care providers (see Hays article). **Lori:** Care coordination definition was discussed in the Services Delivery Model subcommittee. Care coordination is needed across all care. **Marian:** What about severity, considering the trajectory of ups and downs over the course of the child's illness? When would a referral be made for palliative care? **Dr. Spruce**: Maybe when the caregiver and family agree. Some decisions should be left to the SCC. **Lori:** What about when a child is discharged from the hospital? Need to plan ahead to have palliative care referral made before things go badly. **Wendy:** Sometimes palliative care may be needed and sometimes not. Will you consider the child's whole life or just when critical? **Shannon:** What about the family who knows nothing or there is a language barrier? Perhaps palliative care can be tailored to more or less intense as the needs dictate. **Dr. Randle:** Curative treatment may be possible but may fail. **Belva:** Must be able to access at least one waiver service to be in waiver, otherwise the child would not be enrolled in the pilot.	Group agreement to include both diagnosis and level-of-care criteria.

	Dr. Dalsey: We would look at the child at a particular point in time with a prognosis of death before reaching adulthood. **Lori**: Perhaps a merger of hospice with SCC teams could be considered. **Wendy:** In Shasta County, no Home Health Agency services are available to help with intense care. **Sharon:** We do have limited services available in remote areas. **Dr Randle:** Introduced NEJM table outlining *Conditions appropriate for Pediatric Palliative Care.* **Dr. Spruce:** Maybe this is as specific as it should get—using this list with examples. **Dr. Dalsey** pointed out that although CCS case management of rural counties is primarily done by state staff, we can't get additional positions at the state level. Larger counties, however, have the ability in their budgets to allocate additional staff. There are few CCS approved physicians available in rural areas. **Pam** reviewed the handout of *Other States Eligibility Criteria for Pediatric Palliative Care*. **Dr. Dalsey**: The terms l*ife limiting* or *life threatening* definition may be a problem. Perhaps we should remain broad in language. The AAP states that palliative care should be provided to *all children not expected to survive childhood.* **Dr. Dalsey**: Discussed individual financial deeming—where child is enrolled in Medi-Cal regardless of family income. **Lori**: Pediatric palliative care N.L. release will help. Can the child simultaneously be in more than 1 waiver? **Kathy**: No. In the waiver application, we can discuss transitioning into and out of waiver. Will pass recommendations to larger group.	Group settled on NEJM diagnostic categories combined with intensity of services criteria used in the WA model. Next Meeting was tentatively scheduled for March 14, 2007, however since we made significant progress, we will not need to meet at that time.